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Douma, L.N.

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CHAPTER 2

Attitudes, beliefs and knowledge regarding breast, cervical and colorectal cancer screening: A scoping review

Douma LN, Uiters E, Damman OC, Van der Meij AE, Timmermans
DRM.

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Abstract

Objective: By conducting a scoping review, we aimed to gain more insight into people's attitudes, beliefs and knowledge (i.e. the key elements of informed decision-making) regarding breast, cervical and colorectal cancer screening. This could contribute to a better understanding of how to optimise informed decision-making and interventions to increase informed uptake.

Methods: An Embase.com and PsycINFO search was performed (2000 to 2016) to identify articles on people's attitudes, beliefs and knowledge regarding breast, cervical or colorectal cancer. In order to improve the relevance of comparison, we only included studies from OECD countries in Europe, North America or Australia/New Zealand.

Results: Generally, across the three cancer screenings, studies included in our review found that the majority of people had positive attitudes or beliefs towards cancer screening. Mixed results were found across the three cancer screenings concerning people in general having correct or sufficient knowledge about cancer and cancer screening. Overall, the possible harms and risks of cancer screening received relatively little attention. Studies appear to differ in their understanding and assessment of the concepts 'attitudes', 'beliefs' and 'knowledge' and seem to use these terms interchangeably.

Conclusion: Generally, people appear to have positive attitudes and beliefs about cancer screening. However, the concepts of attitudes, beliefs and knowledge were not measured consistently across studies, which makes it difficult to compare results and draw overall definitive conclusions. Research in the field of cancer screening and informed decision-making would benefit from clearer definitions and operationalisations concerning how to assess attitudes, beliefs and knowledge.

1. Introduction

In most Western countries, screening for several types of cancer is available, the most common being for breast, cervical and colorectal cancer (1-3). Many countries even have a screening programme implemented nationally or at the regional, state or provincial levels (4, 5). Population-based cancer screening can reduce the incidence and mortality of the cancer being screened for, which is why it is widely recommended (6-10). However, cancer screening also involves potential downsides, such as false negatives, false positives, overdetetection, and discomfort, pain or risks associated with the screening test (11-15). Whether the possible benefits for an individual outweigh the possible downsides depends on how that individual perceives and values the possible benefits and downsides of cancer screening (16-18). Therefore, experts in the field of cancer screening increasingly consider it important that people make a personal and informed decision concerning cancer screening participation (19, 20). An informed decision is commonly defined as a deliberative decision based on sufficient and relevant knowledge concerning the different choice-options and consistent with the decision-maker's values, often operationalised as their attitude or preferences towards screening (21, 22).

The uptake regarding the different cancer screenings varies across countries worldwide (1-3). A common reason to examine people's attitudes concerning cancer screening has been to increase screening uptake, as a certain uptake is necessary to actually obtain the population benefits of screening (14, 23). Nowadays, personal responsibility and autonomous decision-making has become a prominent facet of modern Western society (24, 25), which is reflected in the origination of concepts such as empowerment (26), self-management (27), shared decision-making (28) and informed decision-making (19) within the domains of medical care as well as public health. With this increased focus on personal responsibility and autonomous decision-making, it is viewed as more important that people are able to make their cancer screening decision in an autonomous and informed manner. This then provided additional reasons, next to increasing screening uptake, to study people's attitudes as well as their beliefs and knowledge concerning cancer screening. Thus far, a fair amount of studies have been conducted covering these

topics (e.g. (29-31)). Many studies suggest an overall positive view towards cancer screening in general, with people viewing cancer screening being a good idea and able to save lives (32-34). Additionally, a number of studies show that people often overestimate the benefits of cancer screening (35, 36). However, there are also studies reporting people to be less positive about screening, to have more fatalistic beliefs about cancer and to have relatively low expectations of early detection (37-40). These different findings could be truly reflective of the mixed views towards cancer screening existing among the population. However, there is also the possibility that these differences are associated with the type of screening being researched. Additionally, these differences might be associated with different ways of examining or assessing people's attitudes, beliefs and knowledge (41, 42).

In general, the Health Belief Model (HBM) (43, 44) and the Theory of Planned Behaviour (TPB) (45) are popular conceptual frameworks to use as they involve people's attitudes, beliefs and or knowledge as core elements. When researching the definition of attitudes in psychological and philosophical literature, the general consensus seems to be that an attitude is a cognitive or mental representation that *summarizes an individual's evaluation* of an attitude object (e.g. a particular person, group, thing, action or idea) (46-48). It is a complex cognitive schema consisting of multiple elements resulting in a general cognitive and affective evaluation of something or someone being positive or negative. Cognitive information (i.e. facts and beliefs about an attitude object), affective information (i.e. feelings, emotions and values regarding an attitude object), and behavioural information (i.e. interactions or experiences with the attitude object) can all contribute to attitude formation (47, 49). Attitudes are considered psychological constructs that cannot be directly observed and are, as a result, usually measured through self-report. Most often, people are presented with a series of Likert-scale statements or a semantic differential scale (50). The sum scores then represent people's attitude towards the attitude object.

Regarding the definition of beliefs, there seems to be more of a debate, with few structured descriptions available. Beliefs are generally described as *cognitions or subjective probabilities* about the world (51, 52). However, they are also sometimes

referred to as mental representations of an attitude (53). Additionally, the term beliefs appears to often be used synonymously with the term perceptions (54). In general, a belief is seen as the simplest form of a mental representation being at the base of conscious thought, with people thinking something to be true, with or without evidence for it being true. Beliefs are also often referred to as a *conviction* or a feeling of certainty that something is true (55, 56). Additionally, people's experiences and values – next to factual information – can be involved in the construction of their beliefs (52, 57). This suggests that it is not merely cognition that matters. Beliefs are usually measured in the same way that attitudes are measured; through self-report and by presenting people with Likert-scale statements or a semantic differential scale.

A commonly held definition of knowledge is that it is a '*justified true belief*' (58, 59), although an ongoing debate exists concerning this (60-63). In general, knowledge is seen as what one believes as well as these beliefs being justified or substantiated by evidence. Another description is that knowledge is a familiarity or understanding (theoretical or practical) of something or someone, which is acquired through education or experience (64, 65). Thus, knowledge does not only exist of factual information, and people can have a range of sources and experiences that will shape their knowledge of the world. Knowledge defined as a belief that is true and justified has led to mainly measuring it according to whether people give correct or incorrect answers to a series of questions or statements, hereby using different answering formats, such as true/not true, multiple choice, or open-ended. However, it has been argued that the certainty an individual has in their given answer is also an essential component of knowledge, which is now often neglected (59).

With the uptake of cancer screening in general in many countries being relatively low (1-3), there is a continuous interest in establishing why this may be and finding ways to optimise interventions to increase (informed) uptake. Hereby, it is pertinent to investigate discrepancies in perceptions among the general cancer screening target population, and to focus on both factors relevant for cancer screening in general and factors relevant for a specific type of cancer screening. Additionally, with people's ability to make autonomous and informed cancer screening decisions increasingly being

considered important, there is a continuous interest for finding ways to optimally assist people in doing so. Gaining more insight into people's attitudes, beliefs and knowledge (i.e. the key elements of informed decision-making) regarding the most common cancer screenings, as well as how these have been examined/assessed within the context of the above described definitions and operationalisations, would contribute to both these objectives. We therefore conducted a scoping review covering studies into people's attitudes, beliefs and knowledge concerning breast, cervical and colorectal cancer screening in order to provide a structured overview of the diverse findings surrounding the complex issue of cancer screening. The corresponding research questions were:

- I. How have studies examined/assessed people's attitudes, beliefs and knowledge (within the context of the above described definitions and operationalisations) concerning breast cancer screening, cervical cancer screening and colorectal cancer screening?
- II. What did studies find regarding people's attitudes, beliefs and knowledge concerning breast cancer screening, cervical cancer screening and colorectal cancer screening?

2. Methods

2.1. Search strategy

Searches were performed using Embase.com (which combines the search engines Embase and Medline; see https://kemh.libguides.com/library/search_tips/faqs/difference_between_pubmed_online_embase for more information) and PsycINFO from 2000 to 2016. Separate searches were conducted for each of the three most common types of cancer screening (breast, cervical and colorectal cancer). Broad search terms related to breast, cervical and colorectal cancer screening (e.g. breast, cervical, uterine, colorectal, bowel, intestine, cancer, carcino) were used in combination with search terms related to attitudes, beliefs and knowledge (e.g. attitude, knowledge, belief, perception, perspective, health behaviour, risk factors; see Appendix C for the detailed search strategies).

2.2. Study selection

Three reviewers working in pairs (LD and AM on breast and cervical screening, LD and DvdIJ on colorectal screening) conducted the study selection independently of each other based first on title, then abstract and then full text, using a predefined protocol. When there was no consensus regarding the abstract selection, a discussion followed until consensus was achieved. LD and AM/DvdIJ both scored half of the full texts and discussed the selection. When there was no consensus, a discussion followed, with EU and OD taking part. Only original, quantitative, peer-reviewed articles were taken into account.

2.3. Selection criteria

The selection process is shown in Figure 1. Articles were selected if they met the following criteria:

- The language of the article is English
- The article is an original article; no editorial, letter to author, review, etc.
- The article is directly related to our research question: attitudes/beliefs/knowledge of lay people regarding breast, cervical and colorectal cancer screening
- In order to improve the relevance of comparison, we only included studies from OECD countries in Europe, North America or Australia/New Zealand, as these are comparable in social and economic status as well as their research tradition in the area of cancer screening
- The study population is representative for the population or multiple (minority) groups are compared to each other
- The study does not include a high-risk population regarding the type of cancer; only a population that would be eligible for the screening programme
- The study does not include cancer patients in their study population
- It is not an intervention study
- It is not a validation study
- It is not a qualitative study

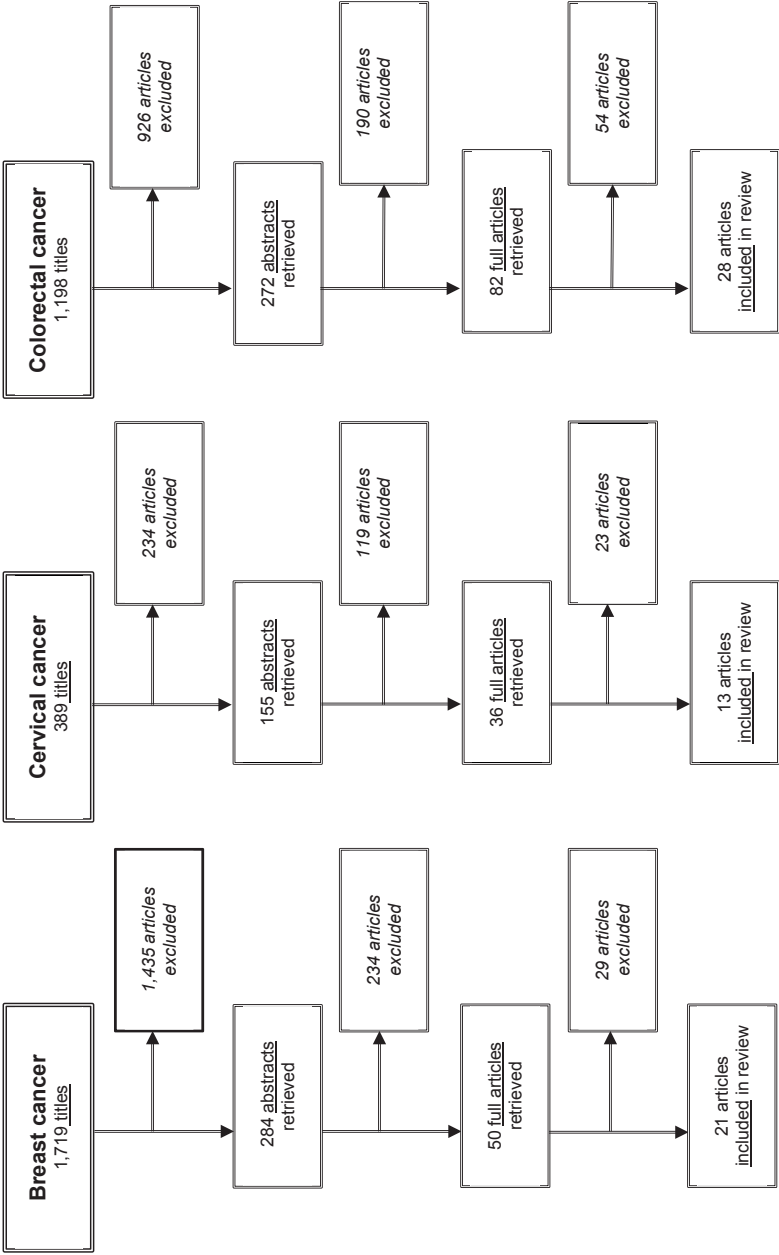


Figure 1. Study selection flow diagram

2.4. Data extraction and analysis

Data extraction was performed by AM, SB, DvdIJ and LD. Data analysis was performed by LD. We used a descriptive approach in analysing the results. This means that when describing and categorising what studies examined and determined regarding people's attitudes, beliefs and knowledge, we were guided by what the authors of the studies reported. Thus, if the authors stated that they examined people's knowledge, we categorized it as knowledge. If they stated that they examined people's attitudes or beliefs, we categorized it accordingly. The same goes for the specific topics being researched within the categories of knowledge, attitudes and beliefs. However, where relevant and possible we did provide overarching themes/terms. Additionally, categorisations of the majority or an equal proportion of the study sample having correct/incorrect knowledge were based on what studies reported. Result sections 3.2 and 3.3 cover the question of how studies examined/assessed people's attitudes, beliefs and knowledge. Result sections 3.4, 3.5 and 3.6 cover the question concerning what studies found regarding people's attitudes, beliefs and knowledge.

3. Results

Regarding breast cancer, 1,719 articles were found, of which 21 were included in the review. Regarding cervical cancer, 389 were found of which 13 were included, and regarding colorectal cancer, 1,198 were found of which 28 were included (see Figure 1).

3.1. Study sample

Table 1 shows the characteristics of the studies included in our review. Most studies ($N = 31$) were conducted in the United States of America (USA), followed by the United Kingdom (UK) and Australia (both $N = 6$). Most studies were conducted in the period 2010-2014 ($N = 22$), used a telephone or face-to-face survey ($N = 45$) and had a sample size of 101-500 ($N = 20$).

Table 1. Characteristics of studies included in the review

Variable	Breast cancer screening	Cervical cancer screening	Colorectal cancer screening
Number of selected studies	21	13	28
Year published			
2000-2004	(31, 66-72)	(73)	(74, 75)
2005-2009	(76-79)	(30, 80-83)	(84-91)
2010-2014	(92-97)	(98-100)	(101-113)
2015-2017	(114-116)	(117-120)	(121-125)
Country			
Australia	(76)	-	(85, 102, 109, 110, 113)
Canada	-	(82)	(106)
Germany	-	(80)	-
Greece	(95)	(99)	-
Ireland	-	(30)	-
Netherlands	-	(83)	(125)
Poland	(116)	(118)	-
Portugal	(96)	-	-
Spain	(94)	-	(104)
Sweden	(31, 115)	(117)	-
Turkey	(92)	(98)	(112)

UK	(72, 77)	(73)	(74, 103, 124)
USA	(66-71, 78, 79, 93, 97, 114)	(81, 100, 119, 120)	(75, 84, 86-91, 101, 105, 107, 108, 111, 121-123)
Method of data collection			
Telephone/face-to-face survey	(31, 66, 68-71, 76, 92, 94-97, 114, 116)	(81, 82, 98-100, 117)	(74, 75, 84-89, 91, 101-109, 111-113, 121-124)
Survey by post	(67, 72, 77-79, 115)	(30, 73, 80, 83)	(110, 123)
Online/web-based survey	(93)	(119, 120)	(90, 125)
Survey (unknown how conducted)	-	(118)	-
Sample size			
1-50	-	-	(75, 88)
51-100	-	-	(87, 109)
101-500	(69, 79, 92, 95, 116)	(73, 81, 82, 98, 99, 118-120)	(84, 102, 103, 105, 112, 123, 124)
501-1000	(31, 67, 70, 71, 77, 94, 96)	(80, 100)	(85, 104, 107, 110, 111, 121, 122)
1001-2000	(66, 72, 93, 115)	(30, 83, 117)	(74, 89, 91, 108, 113, 125)
> 2000	(68, 76, 78, 114)	-	(86, 90, 101, 106)

3.2. The use of the terms ‘attitude’, ‘beliefs/perceptions’, and ‘knowledge’

Across the three cancer screenings (breast, cervical and colorectal), most studies included in our review used the terms ‘beliefs’ and ‘perceptions’ interchangeably/synonymously. This seems commonly accepted considering the definition of beliefs as described in our introduction section. Therefore, in our tables we report the terms ‘beliefs’ and ‘perceptions’ as one and the same (i.e. ‘Beliefs/perceptions regarding [...]’). Moreover, several studies used the terms ‘attitudes’ and ‘beliefs/perceptions’ interchangeably (e.g. (84, 109)). This was also found for the terms ‘knowledge’ and ‘beliefs/perceptions’, with, for example, Philips et al. (2003) (73) referring to the same result in their article as “answers being correct”, “women’s knowledge” and “women’s beliefs”. Comparable cases were seen in several other studies (e.g. (68, 107)). In addition, we found variabilities between studies regarding the understanding of the terms ‘attitudes’, ‘beliefs/perceptions’ and ‘knowledge’ and/or how to assess these concepts. Some studies reported to have examined people’s attitudes or knowledge, while other studies using a similar formulation or approach reported to have examined people’s beliefs. For example, as a measure of attitudes McCaffery et al. (2003) (74) asked people whether they would want to know if they had cancer and about undergoing screening being embarrassing, while others asked these questions as a measure of beliefs (e.g. (84, 85)). Another example is the item ‘Screening is good’ being mentioned as both a measure of attitude (66) and belief (31, 85). Similar examples exist regarding knowledge and beliefs. For instance, as a measure of knowledge, Lagerlund et al. (2000) (31) asked people about the efficacy of screening in detecting cancer early, while Achat et al. (2005) (76) asked this as a measure of beliefs. Furthermore, we found studies that assessed knowledge using formulations that however seemed to be addressing beliefs. For example, as a measure of knowledge Harvey et al. (2015) (114) asked whether the benefits of screening are more important than the risks, and Arnold et al. (2012) (107) asked how helpful people thought it was to find cancer early.

3.3. Ways of assessing

A number of studies included in our review used existing behaviour or decision-making models as a conceptual framework to assess people’s attitudes or beliefs/perceptions.

These were mainly the Health Belief Model (HBM) (31, 67, 75, 79, 87, 95, 98, 105, 107, 109, 110, 121) and the Theory of Reasoned Action/Planned Behaviour (70, 72, 93). All studies using a model as a conceptual framework made certain adjustments to adapt to the specific topic they were researching; they formulated their own questions, added other concepts or questions, or left concepts out that were not considered relevant for their current study objective. Studies not using a conceptual framework to assess attitudes, beliefs or knowledge formulated their own questions or (partly) used items from other studies (e.g. (69, 74, 117)). The existence of different approaches combined with most studies developing their own questionnaires, resulted in people's attitudes, beliefs and knowledge being assessed in many different ways. Sometimes the differences in questioning were quite substantial. For example, Anagnostopoulous et al. (2012) (95) assessed risk perception by asking people to rate their perceived personal lifetime breast cancer risk on a scale ranging from zero (no possibility of getting breast cancer) to 100 (absolutely certain of getting breast cancer). Arnold et al. (2012) (107), on the other hand, assessed risk perception by asking people to what extent on a 4-point scale they agreed with the statement 'I feel I will get colorectal cancer sometime during my life'. There were studies that used composite or sum scores as a measure of attitudes, beliefs or knowledge. When doing so, different combinations of questions were usually used. For example, both Pons-Vigués (2011) (94) and Rahman & Rahman (2008) (79) assessed women's knowledge regarding breast cancer and screening, but each used a different set and number (respectively 6 versus 17) of questions. Even when the same conceptual framework was used as a base, there were differences in the kind and number of questions asked. For instance, both Anagnostopoulous et al. (2012) (95) and Champion & Skinner (2003) (67) used the Health Belief Model as a conceptual framework and assessed people's beliefs concerning the benefits and barriers of breast cancer screening. However, Anagnostopoulous et al. used 4 benefit items and 14 barrier items, whereas Champion & Skinner used 5 benefit items and 11 barrier items. Additionally, Anagnostopoulous et al. assessed people's belief concerning screening increasing their chances of survival, while Champion & Skinner assessed people's belief concerning screening decreasing their chances of dying.

3.4. Attitudes (see Table 2, and the extended version in Appendix A)

Especially regarding colorectal cancer screening, studies assessed people's attitudes towards cancer and cancer screening (e.g. (74, 104)). In general, the questions asked concerned the possible benefits of screening and barriers or reasons not to screen. Multiple questions or items were usually used to assess people's attitudes. For example, McCaffery et al. (2003) (74) asked people to what extent they agreed with the following four statements: 1) I would want to know if I had cancer; 2) I would not want to know if I had cancer; 3) I would not want to know if I had cancer till the very end; 4) Having a colorectal examination would be too embarrassing. Across the three cancer screenings, studies generally found the majority of their study sample to have a positive attitude concerning cancer screening. Three studies on colorectal cancer examined people's attitude regarding cancer. They found that the majority of their study sample believed colorectal cancer to be serious but that possibilities for treatment and prevention also existed.

Table 2. Attitudes and beliefs regarding breast, cervical and colorectal cancer screening

Variables	Breast cancer screening				Cervical cancer screening				Colorectal cancer screening			
	Majority true ¹	Majority not true ²	Equal proportion	Equal true/not true ³	Majority true ¹	Majority not true ²	Equal proportion	Equal true/not true ³	Majority true ¹	Majority not true ²	Equal proportion	Equal true/not true ³
A. Attitudes ^{4, 5}												
Positive attitude towards screening	(31, 94, 115)	-	-	-	(81)	-	-	-	(74, 75, 103, 104, 106, 109, 123-125)	(103)	-	-
Concerned about getting cancer	-	-	-	-	-	-	-	-	(103)	(74, 106, 109)	-	-
Cancer is severe/impacts your life	-	-	-	-	-	-	-	-	(103, 109)	-	-	-
Cancer treatment can be effective	-	-	-	-	-	-	-	-	(106)	(103)	(109)	(109)

Preventive measures can be taken - - - - - (106) - (109)

B. Beliefs/perceptions

Screening recommendations⁴

Aspects referring to current recommendations (66, 70) - (77) - - - (85, 113) - -

Open to extending screening interval - - - - - (119) (81) (100) - - -

Benefits, effectiveness, harms and risks of screening⁴

Screening has benefits/is beneficial (31, 66, 67, 72, 76, 77, 79, 93-96, 114) - - - (83, 98) - - (75, 84, 85, 87-89, 101, 102, 105, 107, 109, 110, 113, 122) -

<i>Screening is effective in detecting cancer (early)</i>	(31, 72, 76, 77)	-	-	-	-	-	(88)	-
<i>Screening might cause harm or discomfort</i>	-	(71, 72)	(70)	-	-	-	(84, 122)	-
<i>A better detection rate would be preferred</i>	(114)	-	-	-	-	-	-	-
<i>The result gives certainty about having or excluding cancer</i>	(31)	(76)	-	-	-	-	-	-

Barriers and self-efficacy concerning screening participation⁴

<i>Barriers are clearly present</i>	-	(31, 67, 94)	(95)	-	(30, 98)	(83)	(75, 84, 87, 88, 105, 107, 110)	-
<i>Certain specific barriers are present</i>	(31, 66, 70-72, 77, 79, 114)	-	-	-	-	-	(85, 88, 89, 109, 111, 112, (84, 107, 113, 121) 121)	(84, 89, 121)

121, 122)

I believe to have sufficient/high self-efficacy (31, 93, 95) - - - - - (87, 89, 90, 107, 110, 122) - -

Cancer, cancer treatment and cancer risk⁵

Cancer is severe/impacts your life (31, 79, 95) - - - - - (75, 84, 121) - -

Cancer treatment can be effective (31, 70, 95) - - - - - (81) (84) (122) - -

Preventive measures can be taken - - - - - - (101, 102) - -

Belief in specific cancer risk factors (66) - - - - - (102) (101)

My risk/susceptibility is high (93) - - - - - (85) - (121)

My risk/susceptibility is low (31, 67, 70, 79, - - - - - (30, 73) - - (75, 84, 89, 105, -

92, 95, 107, 109,
97, 115) 112)

My risk/susceptibility is average (92, 94) - - - (81, 83, 98) - (90, 122) - -

Social environment

Others think I should undergo screening (31, 72) - - - (83) - - (125) - (75, 122)

I experience social support (31) - - - - - (110) - -

¹ Majority of study sample believed/perceived statement to be true
² Majority of study sample believed/perceived statement not to be true
³ Equal proportion of study sample believed/perceived statement to be true/not true
⁴ Concerning breast/cervical/colorectal cancer screening
⁵ Concerning breast/cervical/colorectal cancer

3.5. Beliefs (see Table 2, and the extended version in Appendix A)

Across the three cancer screenings, studies included in our review examined people's beliefs/perceptions regarding: a) Screening recommendations; b) Possible benefits, harms and risks of screening; c) Possible barriers for participating in screening; d) Self-efficacy regarding screening; e) Cancer and cancer treatment; f) Cancer risk and risk factors; g) Social environment.

Screening recommendations

Three studies regarding breast cancer screening and two studies regarding colorectal cancer screening assessed people's beliefs concerning specific elements of when screening is recommended, such as screening age (e.g. (70)) or screening in the absence of a family history of cancer (e.g. (66)). Most of these studies reported the majority of their sample having correct beliefs. Regarding cervical cancer screening, three studies assessed people's beliefs or preferences concerning a potential extension of the screening interval, with mixed findings regarding such an extension being preferred or not (e.g. (100, 119)).

Possible benefits and the effectiveness of cancer screening

Studies often assessed people's beliefs regarding the benefits of cancer screening in general terms, such as 'Screening is good' (e.g. (77)) or 'Screening is beneficial' (e.g. (31)). Additionally, several studies also assessed more specific beliefs, such as 'Screening saves lives' (e.g. (107)), 'Screening leads to early treatment' (e.g. (31)), or 'Regular screening gives me reassurance about my health' (e.g. (77)). Across the three cancer screenings, studies generally found the majority of people to believe that cancer screening was beneficial and effective in detecting cancer early, although only two studies were conducted in the area of cervical cancer screening (83, 98).

Possible harms and risks of cancer screening

Six studies, only regarding breast and colorectal cancer screening, examined people's beliefs concerning the possible harms and risks of screening (e.g. (70)). The majority of these study populations did not believe screening to be harmful. Harvey et al. (2015)

(114) found that women would value mammograms having a better detection rate (i.e. lower false-positives).

Meaning of the test result

Two studies regarding breast cancer screening explicitly assessed people's beliefs about the meaning of the screening test result. Of them, Achat et al. (2005) (76) found that the majority of their study sample believed that a positive test result did not necessarily mean that they had cancer. Lagerlund et al. (2000) (31) found that the majority of their study sample believed that a negative result meant that having cancer was excluded.

Barriers and self-efficacy concerning cancer screening participation

Across the three cancer screenings, studies examined people's beliefs concerning barriers by asking about it in general terms. These studies found that the majority of their study samples believed that barriers were not present (e.g. (94, 105)). Additionally, an equal amount of studies, only in the area of breast and colorectal cancer screening, asked people about specific aspects that could *potentially* be a barrier for participation, but were not necessarily mentioned as an actual barrier. Appendix A shows the main specific potential barriers mentioned. They include costs, painful procedure, fear of finding cancer, embarrassment, scheduling issues, no doctor's referral and not having symptoms (e.g. (70, 88)). Regarding breast and colorectal cancer, ten studies examined people's self-efficacy concerning screening. All found that the majority of people believed they had high or sufficient self-efficacy (e.g. (31, 107)).

Cancer, cancer treatment, cancer risk factors and cancer risk

Mainly studies regarding breast and colorectal cancer screening examined people's specific beliefs about breast or colorectal cancer and its treatment, such as 'Colorectal cancer is the most prevalent cancer' (e.g. (102)), 'Breast cancer has severe consequences' (e.g. (95)), 'Breast cancer treatment is severe' (e.g. (31)), 'Colorectal cancer is not preventable' (e.g. (102)). Similar to what we found for attitudes, results showed that the majority of the studied populations believed breast or colorectal cancer to be serious but also with possibilities for treatment and prevention. Only three studies regarding breast and colorectal cancer screening examined people's beliefs about risk

factors for getting breast or colorectal cancer. Messina et al. (2002) (66) assessed beliefs concerning specific risk factors for breast cancer and found that the majority of people believed in the existence of a range of possible risk factors, such as family history, smoking and living nearby an airport (see Appendix A). Across the three cancer screenings, studies examined people's risk perception. In general, the majority of the people in these studies believed their own risk to be low or average (e.g. (31, 81, 107)).

Social environment

Across the three cancer-screenings, seven studies assessed people's beliefs concerning their social environment. They found that the majority of the people in their study believed that their environment was positive about cancer screening (e.g. (31)), and that they had social support (e.g. (110)).

3.6. Knowledge (see Table 3, and the extended version in Appendix B)

Across the three cancer screenings, studies included in our review examined people's knowledge regarding: a) Screening recommendations or guidelines; b) Breast, cervical or colorectal cancer screening and screening methods; c) Breast, cervical or colorectal cancer, including treatment, cancer risk and risk factors. Most studies assessed people's knowledge by asking them to answer certain questions regarding the subject of interest ('objective knowledge'). However, there were also studies that assessed people's knowledge by asking them to what extent they found themselves knowledgeable or informed about the subject ('self-perceived knowledge'). When assessing self-perceived knowledge, studies mostly found that the majority of their study sample did not consider themselves sufficiently knowledgeable (e.g. (106, 117)).

Table 3. Knowledge regarding breast, cervical and colorectal cancer screening

Variables	Breast cancer screening				Cervical cancer screening				Colorectal cancer screening			
	Majority	Majority	Equal	Majority	Majority	Majority	Equal	Majority	Majority	Majority	Majority	Equal
	correct or sufficient knowledge ¹	incorrect or insufficient knowledge ²	proportion correct-incorrect or sufficient-insufficient knowledge ³	correct or sufficient knowledge ¹	incorrect or insufficient knowledge ²	correct or sufficient knowledge ¹	proportion correct-incorrect or sufficient-insufficient knowledge ³	correct or sufficient knowledge ¹	incorrect or insufficient knowledge ²	correct or sufficient knowledge ¹	incorrect or insufficient knowledge ³	proportion correct-incorrect or sufficient-insufficient knowledge ³
Screening recommendations ⁴	(71, 76, 96, 97)	(31, 69, 71, 76, 95, 96)	(78)	(73, 99)	(81, 99, 119, 120)	(84)	-	(84)	(84, 86, 89, 105)	(84, 86, 89, 105)	(89, 111)	
Cancer screening ⁴	(31, 69, 71, 77, 92, 93, 116)	(68, 71, 96, 114)	-	(30, 73, 117, 119, 120)	(100, 117, 120)	(84, 86, 91, 102, 106-108, 125)	-	(84, 86, 91, 102, 106-108, 125)	(88, 89, 102, 106-109, 112, 122, 125)	(88, 89, 102, 106-109, 112, 122, 125)	(89, 102, 107, 125)	
Cancer and cancer treatment ⁵	(31)	-	(71, 95)	-	(73, 117)	(84, 91, 104, 107-109)	-	(84, 91, 104, 107-109)	(74, 104, 106, 109, 122, 125)	(74, 104, 106, 109, 122, 125)	(104, 125)	

Cancer risk and risk factors ⁵	(116)	(69, 77, 78, 93)	(31, 71)	(73, 119)	(80, 118)	-	(106, 109)	(74, 89, 91, 102)	(74, 125)
Cancer ⁵ and cancer screening/early detection ⁴	-	(67, 79)	(94)	-	(82)	(119)	(87, 108, 110)	-	-

¹ Majority of study sample had correct or sufficient knowledge/awareness

² Majority of study sample had incorrect or insufficient knowledge/no awareness

³ Equal proportion of study sample had correct-incorrect or sufficient-insufficient knowledge/awareness-no awareness

⁴ Concerning breast/cervical/colorectal cancer screening

⁵ Concerning breast/cervical/colorectal cancer

Screening recommendations

Across the three cancer screenings, studies assessed people's knowledge about specific elements of the particular screening recommendations, namely the age at which one should start screening (e.g. (99)), the age at which one should stop screening (e.g. (71)), and the recommended interval of screening (e.g. (84)). Regarding colorectal cancer screening, people were also asked about the recommendations concerning the different screening methods (i.e. stool test, colonoscopy, sigmoidoscopy). For all cancer screenings, there were mixed findings concerning the majority of people having correct or sufficient knowledge about the screening recommendations (e.g. (71, 84, 89)). There were studies that found that the majority of their study sample had sufficient awareness or knowledge, while others did not find this in their study. Especially regarding the starting age of breast cancer screening and the recommended screening interval of colonoscopy and sigmoidoscopy, studies found that the majority of their study sample had incorrect/insufficient knowledge.

Cancer screening and cancer

Several studies examined people's awareness of cancer screening and methods used to screen as part of knowledge, especially in the area of colorectal cancer screening (e.g. (108)). In addition to awareness, studies examined people's knowledge regarding specific elements of cancer screening, such as the purpose of screening (e.g. (119)), the effectiveness of screening (e.g. (68)), the benefits of screening (e.g. (114)), and the harms of screening (e.g. (125)). However, the possible harms and risk of screening received relatively little attention. Again, for all cancer screenings, there were mixed findings concerning the majority of people having correct or sufficient awareness or knowledge about cancer screening and screening methods.

Regarding knowledge about cancer, studies usually examined this by assessing knowledge of specific elements, such as early warning signs (e.g. (109)) or the incidence of the type of cancer in question (e.g. (73)). Four studies also examined knowledge about cancer treatment (e.g. (74)). Additionally, studies assessed people's knowledge in general of the risk factors of breast, cervical or colorectal cancer (e.g. (69)). Again, for all cancer screenings there were mixed findings concerning the majority of people having

correct or sufficient knowledge about cancer, cancer treatment and cancer risk factors. Four studies examined knowledge about the risk (e.g. lifetime risk) of getting breast, cervical or colorectal cancer. None of these studies found that the majority of their study sample had correct or sufficient knowledge (e.g. (74)).

Across the three cancer screenings, there were studies that examined knowledge about breast, cervical or colorectal cancer *together with* knowledge about the corresponding cancer screening, as a combined score. For example, Peterson et al. (2007) (87) examined knowledge about colorectal cancer risk factors, symptoms, screening methods, screening guidelines, detection and treatment as a combined singular variable. Regarding colorectal cancer screening, studies using a combined score found that the majority of their study sample had correct or sufficient knowledge concerning cancer and cancer screening (e.g. (87)), while this result was not found regarding breast and cervical cancer screening studies (e.g. (79, 82)).

4. Discussion

This scoping review covering the topic of people's attitudes, beliefs and knowledge concerning breast, cervical and colorectal cancer screening in mainly Western countries shows that in general more research on this topic has been conducted in the area of breast and colorectal cancer screening than in the area of cervical cancer screening. Overall, studies included in our review found that the majority of people had positive attitudes and beliefs regarding cancer screening. They believed cancer screening to be beneficial and not to involve any harms. Additionally, most people believed breast, cervical and colorectal cancer to be serious but also preventable and treatable, and that they had an average or low risk for getting it. There were mixed findings across the three cancer screenings regarding the majority of people having correct or sufficient knowledge about cancer, cancer screening and screening recommendations.

The main subjects addressed across the three cancer screenings in researching people's attitudes, beliefs and knowledge concerned the benefits of screening, screening recommendations, cancer, cancer risk, and cancer risk factors. The possible harms and

risks of cancer screening received relatively little attention. This was visible within the context of attitudes and beliefs as well as knowledge. This is potentially problematic as informed decision-making – and thus being adequately informed of all relevant aspects concerning cancer screening – has gained increased importance (19). However, some studies seem to have examined people's beliefs about certain possible downsides of screening in terms of beliefs about *potential barriers* for participating in screening (e.g. fear of screening causing harm (70), tests may be inaccurate (88)). Often, people believed these specific aspects of cancer screening to be *potential* barriers; however, most people did not believe there to be *actual* barriers for screening participation.

Most studies included in our review developed their own questionnaires or made specific amendments to existing conceptual frameworks to assess various aspects of attitudes, beliefs and knowledge. While adjusting to the specific topic and question being researched appears desirable in general, this might have led to the sometimes substantial differences in operationalisation that we found between various studies (e.g. number and kind of items used, formulation, ways of scoring; e.g. (67, 79, 94, 95, 107)). These different approaches could affect the conclusions drawn about people's attitudes, beliefs and knowledge regarding the three cancer screenings (41, 42). Additionally, studies included in our review appear to use the terms 'attitudes', 'beliefs/perceptions' and 'knowledge' interchangeably and to vary in their understanding of these concepts (e.g. (68, 73, 84)). This could be a reflection of the ongoing debate regarding the definitions of especially beliefs and knowledge. However, the different uses and understandings of these concepts can be problematic as it is not always obvious what exactly has been examined and to what extent this is similar or different to what other studies have examined.

Our review covered studies that seem to have followed the definition and operationalisation of attitudes as outlined in our introduction section (e.g. (94)), but also studies that seem to have had a different approach. For example, Lagerlund et al. (2000) (31) assessed a set of people's beliefs concerning breast cancer screening using the Health Belief Model as a conceptual framework, but used both the terms beliefs and attitudes. Sirovich et al. (2005) (81) pose a different example where beliefs and

preferences about the interval of cervical cancer screening were considered as attitudes. When comparing the definitions and operationalisations of attitudes and beliefs as outlined in our introduction section, it is evident that there is overlap between the two concepts. Both attitudes and beliefs can be used to assess whether people view cancer screening in a more or less positive manner. This makes it understandable why many studies would use these terms or concepts interchangeably. However, there is a difference in objective when examining people's beliefs or attitudes. Attitudes are in essence evaluative and are more complex than beliefs, as attitudes are a combination of multiple elements. They are used to establish a general and overarching judgement about, in this case, cancer screening (ideally covering both the possible benefits and downsides of screening (19, 126, 127)). In addition to feelings and experiences, beliefs are the underlying thoughts and considerations associated with this judgement. Beliefs refer to people's cognitions and their thoughts concerning simple or specific elements of, in this case, cancer screening or cancer. These specific cognitions are essential to know when the objective is to affect or alter people's behaviour.

In our review, we also found studies using the terms or concepts of beliefs and knowledge differently. For example, Lagerlund et al. (2000) (31) assessed people's knowledge of the efficacy of screening in detecting cancer early, while Achat et al. (2005) (76) asked this as a measure of beliefs. When comparing the definitions of beliefs and knowledge as outlined in our introduction section, we see that both refer to cognitive processes and a conviction of what the truth is. Both beliefs and knowledge can be measured by presenting a series of statements to which people have to indicate, respectively, to what extent they agree with it (i.e. believe it to be true) or whether they think it is true or not. These were also common ways of measuring beliefs and knowledge in the studies included in our review. Additionally, some studies included in our review measured knowledge using a multiple-choice (e.g. (77)) or open-ended answering format (e.g. (74)). Sometimes studies used a difference in wording to indicate beliefs or knowledge being measured, usually incorporating something along the lines of "Do you think/believe that..." as part of a belief statement (e.g. (122)). However, this was not always the case (e.g. (122)), nor can all statements always be adjusted in this way. Generally, studies included in our review often measured beliefs and knowledge in

basically the same way, with the only difference being the authors stating that they were measuring beliefs or knowledge. This may be problematic if, for example, studies that state that they are examining knowledge are taken more seriously, while studies examining beliefs could be providing the same information. It is problematic when value-related statements are addressed as knowledge (i.e. they have a true and justified answer), such as whether the benefits of screening are more important than the risks (114). The main difference in the definitions of beliefs and knowledge as outlined in our introduction section appears to be that knowledge is a belief that is justified by evidence. Although not explicitly part of the outlined definition of knowledge, this evidence is usually interpreted as scientific evidence or expert findings. In other words, a belief that is in agreement with what experts view as being true is equivalent to having knowledge. Subsequently, a belief that is not in agreement with experts' views is equivalent to not having knowledge, or in other words simply a belief. This suggests that the distinction between beliefs and knowledge, especially when measured merely through a series of questionnaire statements without additional context, is primarily theoretical (128). When discussing people's decisions and behaviour, it could be argued that they would rather rely on what they believe to be true and believe to have as 'knowledge' than on scientific facts alone (45, 129-131). Therefore, a solution would be to only speak about measuring people's beliefs and, in light of being adequately informed, whether they are in agreement with experts' opinion or not.

Another complication associated with the use of the concepts 'beliefs' and 'knowledge' and making statements about people having sufficient knowledge in the context of informed decision-making is the fact that among experts in the field of cancer screening there is not yet a commonly held agreement on what constitutes necessary and sufficient knowledge. General guidelines have been issued (19, 126, 127), but there is an ongoing discussion regarding what exactly people ought to know in order to be adequately informed about cancer screening in general as well as a particular type of cancer screening. Therefore, studies often use different knowledge questions (29, 68, 93, 132, 133), different outcome measures (29, 68, 93, 132, 133) and different cut-off points (29, 133). Perhaps these different approaches, at least partly, explain why, for the

three cancer screenings, we found mixed results across studies regarding the majority of people having correct or sufficient knowledge about various subjects (41, 42).

This review has several limitations. Firstly, the review was limited to only scientific articles published in English and studies from OECD countries in Europe, North America or Australia/New Zealand (thus, OECD countries Korea, Japan, Mexico, Chile and Israel were not included). Secondly, although qualitative articles can provide useful insights, they were not included in the review, as the examination of attitudes, beliefs and knowledge are often highly intertwined in this type of study design (in both assessment and reporting). Thirdly, we excluded intervention studies as they often only reported whether an intervention had an effect on people's attitudes, beliefs or knowledge. Fourthly, as we performed a scoping review and not a systematic review, we did not perform a quality analysis of how the studies were conducted. Therefore, findings of studies of less quality are weighed the same as findings of studies of better quality, possibly affecting our results. Finally, in our analysis we did not explicitly consider the possible differences between countries, or states/regions, regarding the target population and execution of cancer screening. People's attitudes, beliefs and knowledge about cancer screening might especially be affected by whether the government, or a similar institute, is responsible for organising it or that people have to arrange it and pay for it themselves. At face value, there seem to be similar findings between countries; however, we did not analyse this systematically.

5. Conclusion

This review provides an overview of people's attitudes, beliefs and knowledge (i.e. the key elements of informed decision-making) concerning breast, cervical and colorectal cancer screening. Generally, people appear to have positive attitudes and beliefs about cancer screening. Mixed results were found regarding whether people had sufficient knowledge about cancer and cancer screening. However, the concepts of attitudes, beliefs and knowledge not being measured consistently across studies makes it difficult to compare different study results, draw overall definitive conclusions and build upon previous findings. Research in the field of cancer screening and informed decision-

making would benefit from clearer definitions and operationalisations concerning how to assess attitudes, beliefs and knowledge. Additionally, it would be beneficial if experts reached a consensus on what constitutes necessary and sufficient knowledge for making an informed screening decision.

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*attitude towards
screening*

I have a positive collective - - - - - (125) - -

*attitude towards
screening*

I have a positive attitude (104) - -

towards undergoing FOBT

I have a positive attitude (75, 104) - -

*towards undergoing
colonoscopy*

Screening is (115) - - - - -

good/important

Screening is not needed if - - - - - (111) -

symptoms are not present

Cancer screening is (103) - - - - -

effective in detecting

cancer (early)

Getting tested is not - - - - -
worth it; what will be, will (103) - - - - -
be

If cancer is found early, it - - - - -
can be treated (106, 109) - - - - -
successfully/improves
your chances of survival

I would want to know if I - - - - -
had cancer (74) - - - - -

I would not want to know - - - - -
if I had cancer (74, 111) - - - - -

I would not want to know - - - - -
if I had cancer till the very (74) - - - - -
end

<i>I prefer not knowing I have cancer to being subjected to cancer treatments</i>	-	-	-	-	-	-	-	-	-	(106)	-
<i>Talking to my doctor about screening is embarrassing</i>	-	-	-	-	-	-	-	-	-	(106)	-
<i>I am afraid the screening tests will be painful</i>	-	-	-	-	-	-	-	-	-	(106)	-
<i>It is too much hassle to prepare for the screening tests</i>	-	-	-	-	-	-	-	-	-	(106)	-
<i>The idea of the test is unpleasant</i>	-	-	-	-	-	-	-	-	-	(106, 124)	-
<i>Having a stool-test/colorectal examination would be</i>										(74)	-

<i>embarrassing</i>									
<i>The self-test/stool-test/preparation is easy to perform</i>								(103, 124)	-
<i>I am afraid of having to use a colostomy</i>								-	(106)

Towards cancer⁵

<i>The thought of cancer is frightening</i>	-	-	-	-	-	-	-	(103)	(74, 106, 109)	-
<i>Cancer is severe/impacts your life</i>	-	-	-	-	-	-	-	(103)	-	-
<i>I am very concerned about the possibility of getting cancer</i>	-	-	-	-	-	-	-	-	(106)	-

<i>Breast/cervical/colorectal cancer is one of the worst cancers you can get</i>	-	-	-	-	-	-	-	-	(106)	-
<i>I would feel ashamed if I had cancer</i>	-	-	-	-	-	-	-	-	(109)	-
<i>Getting cancer is a death sentence</i>	-	-	-	-	-	-	-	-	-	(109)
<i>Getting cancer changes your whole life</i>	-	-	-	-	-	-	-	(109)	-	-
<i>Cancer is something you survive and live with</i>	-	-	-	-	-	-	-	(106)	-	-
<i>You can do a lot to prevent getting cancer</i>	-	-	-	-	-	-	-	(106)	-	-
<i>There is nothing you can do to prevent getting cancer</i>	-	-	-	-	-	-	-	-	-	(109)

B. Beliefs/perceptions

Cancer screening
recommendations⁴

<i>Screening is only needed when a doctor recommends it</i>	-	(70)	-	-	-	-	-	-	-
<i>Screening is only needed when experiencing problems/symptoms</i>	-	(70)	-	-	-	-	-	(113)	-
<i>Screening is needed even when there is no family history of cancer</i>	(66)	-	-	-	-	-	(85)	-	-
<i>Getting screened once is enough</i>	-	(70)	(77)	-	-	-	-	-	-
<i>Screening is best for women/men under 50</i>	-	(70)	-	-	-	-	-	-	-

years old

Women over <u>and</u> under 65 years both need mammograms	(70)	-	-	-	-	-	-	-
I am open to an extension of the screening interval	-	-	-	-	(81)	(100)	-	-
Extending the screening interval would cause worry about getting cancer	-	-	-	-	-	-	-	-
Extending the screening interval would increase the chance of dying of cancer	-	-	-	-	-	(100, 119)	-	-
Extending the screening interval would prevent me from getting other needed	-	-	-	-	(100, 119)	-	-	-

health care

Extending the screening interval would save time and costs	-	-	-	-	-	(100)	-	-	-	-
Extending the screening interval would give peace of mind	-	-	-	-	-	(100)	-	-	-	-
I would prefer getting screened more often	-	-	-	-	-	(81)	-	-	-	-
I would prefer to continue screening after the recommended age	-	-	-	-	-	(81)	-	-	-	-
The recommendations are based on scientific evidence	-	-	-	-	-	(81)	-	-	-	-

<i>The recommendations are based on costs</i>	-	-	-	-	-	-	(81)	-	-	-
<hr/>										
Possible benefits and effectiveness of cancer screening⁴										
<i>Screening is (very) good/important/valuable/positive</i>	(31, 77, 96, 114)	-	-	-	-	-	-	-	(85)	-
<i>Screening has benefits/is beneficial</i>	(31, 67, 79, 94, 95, 134)	-	-	-	(98)	-	-	-	(105, 109, 122)	-
<i>FOBT has benefits/is beneficial</i>									(87, 110)	-
<i>Colonoscopy has benefits/is beneficial</i>									(75, 87)	-
<i>Screening is effective in</i>	(31, 72,	-	-	-	-	-	-	-	(85, 89, 88)	-

<i>detecting cancer (early)</i>	76, 77)							110)	
<i>I would want to know if I had cancer</i>	-	-	-	-	-	-	-	(84, 85, 107)	-
<i>Screening is effective in detecting non-cancerous abnormalities</i>	(72)	-	-	-	-	-	-	(107)	-
<i>Screening saves lives/prevents cancer deaths</i>	(31, 76, 93)	-	-	-	-	-	-	(107, 113)	-
<i>Treating cancer in an early stage will increase your life expectancy</i>	-	-	-	-	-	-	-	(102)	-
<i>Screening increases the chance of successfully treating cancer</i>	-	-	-	(83)	-	-	-	(85, 88, 101)	-

<i>I feel a personal moral obligation to participate</i>	-	-	-	-	-	-	-	-	(83)	-	-	-
Possible harms and risks of cancer screening⁴												
<i>Screening might cause harm/has risks</i>	-	(71)	(70)	-	-	-	-	-	(84, 122)	-	-	-
<i>If done incorrectly, a mammogram can cause cancer</i>	-	-	(70)									
<i>I would value a screening test with a better detection rate/lower false-positives</i>	(114)	-	-	-	-	-	-	-	-	-	-	-
<i>Screening comes with discomfort</i>	-	(72)	-	-	-	-	-	-	-	-	-	-

Meaning of the test result of cancer screening ⁴									
A positive test result always means one has cancer	-	(76)	-	-	-	-	-	-	-
A negative test result excludes cancer	(31)	-	-	-	-	-	-	-	-
Barriers concerning participation in cancer screening ⁴									
Barriers [emotional and practical] are clearly present	-	(67, 94)	(95)	-	(30, 98)	(83)	-	(88, 105)	-
Regarding FOBT: Barriers [emotional and practical] are clearly present							-	(87, 107, 110)	-

Regarding colonoscopy: Barriers [emotional and practical] are clearly present									(75, 87)	-
Emotional barriers are clearly present	-	(31)	-	-	-	-	-	-	-	-
I have a preference for a 'take-home test'									(111)	-
Screening involves a simple examination	(31)	-	-	-	-	-	-	-	-	-
Screening is not inconvenient	(77)	-	-	-	-	-	-	-	-	-
A potential main barrier for me is:										
- Costs	(114)	-	-	-	-	-	-	-	(88, 111,	-

- Lack of adequate insurance	(114)	-	-	-	-	-	-	-	121)	(111)	-	-
- Difficulty to arrange transport	(72)	-	-	-	-	-	-	-	-	(121)	-	-
- Scheduling issues	(72)	-	-	-	-	-	-	-	(85, 88, 111)	(121)	-	-
- Painful procedure/fear of pain or discomfort	(31, 70)	-	-	-	-	-	-	-	(88)	(84, 121)	-	-
- Fear of screening causing harm/complications	(70)	-	-	-	-	-	-	-	-	(121)	-	-
- Fear of finding cancer/something wrong	(70)	-	-	-	-	-	-	-	(88, 109)	(107, 113, 121)	(84, 89)	-
- Fear of hospitals	(70)	-	-	-	-	-	-	-	-	-	-	-
- Embarrassment	(70)	-	-	-	-	-	-	-	(85, 88)	(84, 121)	-	-
- Preparations involved									(88)	-	(121)	-
- Need for sedation									(121)	-	-	-
- Not understanding how to do the self-test									(109)	-	-	-
- Not having an appropriate place to store									(109)	-	-	-

[illegible][illegible]

[illegible]

sufficient/high self-
efficacy

Cancer and cancer treatment ⁵									
Breast/cervical/colorectal cancer is the most prevalent cancer	-	-	-	-	-	-	-	-	(102)
Cancer is severe/has severe consequences	(79, 95)	-	-	-	-	-	-	(75, 121)	-
Breast/cervical/colorectal cancer is more severe than other forms of cancer	(31)	-	-	-	-	-	-	-	-
Cancer is harmful	-	-	-	-	-	-	-	(84)	-
The cancer treatment is severe	(31)	-	-	-	-	-	-	-	-

<i>The cancer treatment can be effective</i>	-	(31, 95)	-	-	-	-	-	-	-	-
<i>Cancer cannot be cured</i>	-	(70)	-	-	-	-	-	-	-	(84)
<i>Most people diagnosed with cancer will die within 5 years</i>	-	-	-	-	-	-	-	-	-	(81)
<i>There is a big chance of losing one's breast if one has breast cancer</i>	-	(31)	-	-	-	-	-	-	-	-
<i>Cancer is not preventable</i>	-	-	-	-	-	-	-	-	-	(102)
<i>Cancer fatalism</i>	-	-	-	-	-	-	-	-	-	(122)
<i>There is not much you can do to lower your chance of getting cancer</i>	-	-	-	-	-	-	-	-	-	(101)

Cancer risk factors⁵

Cancer is most often caused by a person's behaviour or lifestyle	-	-	-	-	-	-	-	-	(101)	-
<u>A risk factor is:</u>										
- Having a prior history of breast/cervical/colorectal cancer	(66)	-	-	-	-	-	-	-	-	-
- Having a relative with breast/cervical/colorectal cancer	(66)	-	-	-	-	-	-	-	-	-
- Smoking cigarettes	(66)	-	-	-	-	-	-	-	-	-
- Diet-related	(66)	-	-	-	-	-	-	-	(102)	-
- Living near chemical plants/landfills	(66)	-	-	-	-	-	-	-	-	-
- Drinking contaminated water	(66)	-	-	-	-	-	-	-	-	-
- Pesticides/insecticides in environment	(66)	-	-	-	-	-	-	-	-	-

- Living near airports	(66)	-	-	-	-	-
- Living near high tension wires/transmitters	(66)	-	-	-	-	-
- Fibrocystic disease	(66)	-	-	-	-	-
- Oestrogen preparations	(66)	-	-	-	-	-
Cancer risk ⁵						
My risk/susceptibility is high	(93)	-	-	-	(85)	(121)
My risk/susceptibility is low	(31, 67, 70, 79, 92, 95, 97, 115)	-	(30, 73)	-	(75, 84, 89, 105, 107, 109, 112)	-
My risk/susceptibility is average/not high or low	(92, 94)	-	(81, 83,	-	(90, 122)	-
My risk is 50% or less	(92)	-	98)	-	-	-
Social environment						

CHAPTER 2

<i>Others in my environment think I should undergo screening</i>	(31)	-	-	-	-	(110, 125)	-	(122)
<i>My partner/family thinks I should undergo screening</i>	(72)	-	-	(83)	-	-	-	(75)
<i>GP thinks one should undergo screening</i>	-	-	-	(83)	-	-	-	-
<i>I experience social support</i>	(31)	-	-	-	-	(110)	-	-

¹ Majority of study sample believed/perceived statement to be true

² Majority of study sample believed/perceived statement not to be true

³ Equal proportion of study sample believed/perceived statement to be true/not true

⁴ Concerning breast/cervical/colorectal cancer screening

⁵ Concerning breast/cervical/colorectal cancer

Appendix B

Table 3 (extended version). Knowledge regarding breast, cervical and colorectal cancer screening

Variables	Breast cancer screening				Cervical cancer screening				Colorectal cancer screening			
	Majority	Majority	Equal	Majority	Majority	Majority	Equal	Majority	Majority	Majority	Equal	Majority
	correct or	incorrect	proportion	correct or	incorrect	correct or	proportion	incorrect	correct or	incorrect	proportion	incorrect
	sufficient	or	correct-	sufficient	or	sufficient	correct-	sufficient	sufficient	or	correct-	correct-
	knowledge	insufficient	incorrect	knowledge	insufficient	knowledge	incorrect	knowledge	knowledge	insufficient	incorrect	incorrect
	/	knowledge	or	/	knowledge	/	or	knowledge	/	knowledge	or	or
	awareness	/ no	sufficient-	awareness	/ no	awareness	sufficient-	awareness	awareness	/ no	sufficient-	sufficient-
	¹	awareness	insufficient	¹	awareness	¹	insufficient	¹	¹	awareness	insufficient	insufficient
		²	knowledge		²	²	knowledge		²	²	knowledge	knowledge
			/			/	/			/	/	/
			awareness			awareness	awareness-			awareness-	awareness-	awareness-
			-no			-no	no			no	no	no
			awareness			awareness	awareness			awareness	awareness	awareness
			³			³	³			³	³	³

Cancer screening
recommendations⁴

Awareness of screening recommendations - - - - (81, 119) - -

Knowledge of screening recommendations in general - - - - (105) -

Self-perceived knowledge of screening recommendations - - - - (111)

Age at which one should start screening (97) (71, 76, 95, 96) (78) (73, 99) - - (84, 86) -

Age at which one should stop screening (71) (76) (99) - - -

Interval of screening

- Mammography	(71, 76, 96, 97)	(31, 69)											
- Pap smear				(73)	(99, 120)	-							

- FOBT/FIT								(84)	(86)	(89)
- Colonoscopy								-	(84, 86, 89)	-
- Sigmoidoscopy								-	(84, 86, 89)	-
Cancer screening⁴										
Awareness of screening	-	-	-	-	-	-	-	(102, 108, 125)	-	-
Awareness of screening methods in general	-	-	-	-	-	-	-	(86, 102, 106-108)	(88, 112)	(89, 107)
Knowledge of methods of (early) cancer detection	(93, 116)	(71, 96)	-	-	-	-	-	(125)	-	-
Awareness of screening method FOBT/FIT								(84, 86)	(89, 102, 106-109, 122)	-
Awareness of screening method colonoscopy								(84, 86, 106-108)	(89, 122)	(102)

CHAPTER 2

<i>Awareness of screening method sigmoidoscopy</i>							(84, 86)	(89, 102, 107, 108)	-
<i>Existence/procedure of additional testing</i>	-	-	-	-	-	-	-	(125)	-
<i>Self-perceived knowledge in general</i>	-	-	-	-	-	(117)	-	-	(125)
<i>Self-perceived knowledge regarding benefits of screening</i>	-	-	-	-	-	-	(125)	-	-
<i>Self-perceived knowledge regarding harms and risks of screening</i>	-	-	-	-	-	-	-	(125)	-
<i>Self-perceived knowledge regarding screening procedure</i>	-	-	-	-	-	-	-	-	(125)
<i>What is the purpose of</i>	(77, 92, 93)	(96)	-	(30, 117,	(100, 120)	-	(106)	-	-

screening						119)
How does screening work	(93)	-	-	-	-	(119)
Effectiveness of screening	(31)	(68)	-	-	(91, 107)	(125)
Influence of screening on risk of getting breast/cervical/colorectal cancer	-	(68)	-	-	-	-
Screening in the presence or absence of symptoms	(69)	-	-	-	-	(106)
Benefits of screening	-	(114)	-	-	(125)	-
Harms and/or risks of screening	-	-	-	-	-	(125)
Participation being one's personal choice	-	-	-	-	(125)	-

Meaning of the test result	-	-	-	(73, 119)	-	-	(125)	-	-
The occurrence of false-negatives	(77)	-	-	-	-	-	-	-	-
The occurrence of abnormal test results	-	-	-	-	(73)	-	-	-	-
Personal costs & health insurance coverage of screening	-	(114)	-	-	-	-	-	-	-
Effectiveness of breast self-examination	(71)	-	-						
Screening relevance for vaccinated and unvaccinated women				(120)	-	-			

Cancer ⁵									
Awareness of breast/cervical/colorectal cancer	-	-	-	-	-	-	(84, 107-109)	-	-
Cancer in general	-	-	-	-	-	-	(104)	(122)	-
Self-perceived knowledge in general	(31)	-	-	-	(95)	(117)	-	(106)	-
Incidence of breast/cervical/colorectal cancer	-	-	-	-	-	(73)	-	-	(125)
Incidence of breast/cervical/colorectal cancer deaths	-	-	-	-	-	(73)	-	(125)	-
Survival rate when cancer has developed	-	-	-	-	-	-	(91)	-	-

What is breast/cervical/colorectal cancer - - - - - (109) -

Early warning signs of cancer - - - - - (109) (74, 104) -

There is not much you can do to reduce your chance of getting cancer - - - - - (91) - - - - -

What are polyps - - - - - (109) -

Cancer treatment⁵

Knowledge in general - - - - - (71) - - - - - -

Treatment survival rates - - - - - (74) (104)

Genital HPV infection can cause cervical cancer in women - - - - - (119)

Cancer risk⁵									
<i>Lifetime risk</i>	-	(77)	-	-	-	-	(74)	(125)	
<i>Age most at risk</i>	-	-	-	-	-	-	(89)	(74)	
Cancer risk factors⁵									
<i>Knowledge in general</i>	(116)	(69, 78, 93)	(31, 71)	(73)	(80, 118)	-	(106, 109)	(74, 91, 102)	-
<i>Self-perceived knowledge in general</i>	-	-	-	-	(80)	-	-	-	-
<i>Genital HPV infection can cause cervical cancer in women</i>				(119)	-	-			
Cancer⁵ and cancer screening/early detection⁴									

<i>Knowledge in general</i>	-	(67, 79)	(94)	-	(82)	(119)	(87, 108, 110)	-
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¹ Majority of study sample had correct or sufficient knowledge/awareness
² Majority of study sample had incorrect or insufficient knowledge/no awareness
³ Equal proportion of study sample had correct-incorrect or sufficient-insufficient knowledge/awareness-no awareness
⁴ Concerning breast/cervical/colorectal cancer screening
⁵ Concerning breast/cervical/colorectal cancer

Appendix C

Search strategies for Embase.com and PsycINFO (10 February 2017)

A. Embase.com Session

No. Query

#78

#72 OR #77

#75 AND (2000:py OR 2001:py OR 2002:py OR 2003:py OR 2004:py OR 2005:py OR 2006:py OR 2007:py OR 2008:py OR 2009:py OR 2010:py OR 2011:py OR 2012:py OR 2013:py OR 2014:py OR 2015:py OR 2016:py OR 2017:py) AND 'review'/it

#77

#76 #74 OR #75 AND [humans]/lim

#75 #73 NOT #27

#74 #21 AND #73

#73 #36 AND #45

#70 AND (2000:py OR 2001:py OR 2002:py OR 2003:py OR 2004:py OR 2005:py OR 2006:py OR 2007:py OR 2008:py OR 2009:py OR 2010:py OR 2011:py OR 2012:py OR 2013:py OR 2014:py OR 2015:py OR 2016:py OR 2017:py)

#72

#71 #69 OR #70 AND [humans]/lim

No. Query

#70 **#68 NOT #27**

#69 **#21 AND #68**

#68 **#30 AND #45**

#67 **#61 OR #66**

#66 **#64 AND (2000:py OR 2001:py OR 2002:py OR 2003:py OR 2004:py OR 2005:py OR 2006:py OR 2007:py OR 2008:py OR 2009:py OR 2010:py OR 2011:py OR 2012:py OR 2013:py OR 2014:py OR 2015:py OR 2016:py OR 2017:py) AND 'review'/it**

#65 **#63 OR #64 AND [humans]/lim**

#64 **#62 NOT #27**

#63 **#21 AND #62**

#62 **#36 AND #44**

#61 **#59 AND (2000:py OR 2001:py OR 2002:py OR 2003:py OR 2004:py OR 2005:py OR 2006:py OR 2007:py OR 2008:py OR 2009:py OR 2010:py OR 2011:py OR 2012:py OR 2013:py OR 2014:py OR 2015:py OR 2016:py OR 2017:py)**

#60 **#58 OR #59 AND [humans]/lim**

#59 **#57 NOT #27**

#58 **#21 AND #57**

No.	Query
#57	#30 AND #44
#56	#51 OR #56
	#55 AND (2000:py OR 2001:py OR 2002:py OR 2003:py OR 2004:py OR 2005:py OR 2006:py OR 2007:py OR 2008:py OR 2009:py OR 2010:py OR 2011:py OR 2012:py OR 2013:py OR 2014:py OR 2015:py OR 2016:py OR 2017:py) AND 'review'/it
#54	#53 OR #54 AND [humans]/lim
#53	#52 NOT #27
#52	#21 AND #52
#51	#36 AND #43
#50	#49 AND (2000:py OR 2001:py OR 2002:py OR 2003:py OR 2004:py OR 2005:py OR 2006:py OR 2007:py OR 2008:py OR 2009:py OR 2010:py OR 2011:py OR 2012:py OR 2013:py OR 2014:py OR 2015:py OR 2016:py OR 2017:py)
#49	#47 OR #48 AND [humans]/lim
#48	#46 NOT #27
#47	#21 AND #46
#46	#30 AND #43

No. Query

#45	'large intestine tumor'/exp/mj
#44	'intestine tumor'/exp/mj OR 'colorectal cancer'.ti OR 'bowel cancer'.ti OR 'colon cancer'.ti OR 'intestin* cancer'.ti
#43	'breast cancer'/exp/mj
#42	#35 OR #41
#41	#40 AND (2000:py OR 2001:py OR 2002:py OR 2003:py OR 2004:py OR 2005:py OR 2006:py OR 2007:py OR 2008:py OR 2009:py OR 2010:py OR 2011:py OR 2012:py OR 2013:py OR 2014:py OR 2015:py OR 2016:py OR 2017:py) AND 'review'/'it
#40	#38 OR #39 AND [humans]/lim
#39	#37 NOT #27
#38	#21 AND #37
#37	#1 AND #36
#36	#2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #11 OR #12
#35	#34 AND (2000:py OR 2001:py OR 2002:py OR 2003:py OR 2004:py OR 2005:py OR 2006:py OR 2007:py OR 2008:py

No.	Query
	OR 2009 :py OR 2010 :py OR 2011 :py OR 2012 :py OR 2013 :py OR 2014 :py OR 2015 :py OR 2016 :py OR 2017 :py)
#34	#32 OR #33 AND [humans]/lim
#33	#31 NOT #27
#32	#21 AND #31
#31	#1 AND #30
#30	#3 OR #6 OR #11 OR #12 OR #28 OR #29
#29	#4 AND #7
#28	#2 AND #5
#27	#22 OR #23 OR #24 OR #25 OR #26
#26	'gulf of mexico'/exp
#25	'antarctica'/exp
#24	'arctic'/exp
#23	'central america'/exp
#22	'africa'/exp
#21	#13 OR #14 OR #15 OR #16 OR #17 OR #18 OR #19 OR #20

No. Query

#20 **'turkey (republic)'/exp**

#19 **'korea'/exp**

#18 **'japan'/exp**

#17 **'israel'/exp**

#16 **'chile'/exp**

#15 **'australia and new zealand'/exp**

#14 **'north america'/exp**

#13 **'europe'/exp**

#12 **perspective*:ti**

#11 **#8 OR #9 AND #10**

#10 **perception*:ti OR risk*:ti**

#9 **'perception'/exp/mj**

#8 **'risk management'/exp**

#7 **knowledg*:ti**

#6 **belief*:ti OR believ*:ti**

No. Query

#5	attitude*:ti
#4	'knowledge'/exp/mj
#3	'health behavior'/exp/mj
#2	'attitude'/exp/mj
#1	'uterine cervix cancer'/exp/mj

B. PsycINFO session

Databases: PsycINFO

Set#	Searched for
S5	(mjsub(breast neoplasms) AND ti(breast* or mamm*)) and (pd(20000101-20170228))
S6	mjsub(perception) AND ti(percep*)
S7	mjsub(risk management) AND ti(risk*)
S18	mjsub(health behavior) AND ti(behav* AND health*)
S19	mjsub(health knowledge) AND ti(health* and knowled*)
S20	mjsub(health attitudes) AND ti(health* AND attitu*)

S21	mjsub(risk factors) AND ti(risk* AND factor*)
S22	mjsub(knowledge level) AND ((knowned* AND level*))
S23	(S5 AND (S6 OR S7 OR S18 OR S19 OR S20 OR S21 OR S22))

* Duplicates are removed from the search, but included in the result count.

Duplicates are removed from the search and from the result count.

Databases: PsycINFO

Set#	Searched for
S6	mjsub(perception) AND ti(percep*)
S7	mjsub(risk management) AND ti(risk*)
S18	mjsub(health behavior) AND ti(behav* AND health*)
S19	mjsub(health knowledge) AND ti(health* and knowled*)
S20	mjsub(health attitudes) AND ti(health* AND attitu*)
S21	mjsub(risk factors) AND ti(risk* AND factor*)
S24	ti(cervi* OR uterus* OR uteri*) AND (cancer* OR neoplas* OR carcino*)
S26	mjsub(knowledge level) AND ti(knowled* AND level*)
S27	(S24 AND (S6 OR S7 OR S18 OR S19 OR S20 OR S21 OR S26))
S28	((S24 AND (S6 OR S7 OR S18 OR S19 OR S20 OR S21 OR S26))) and (pd(20000101-20170228))

* Duplicates are removed from the search, but included in the result count.

Duplicates are removed from the search and from the result count.

Databases: PsycINFO

Set#	Searched for
S6	mjsub(perception) AND ti(percep*)
S7	mjsub(risk management) AND ti(risk*)
S18	mjsub(health behavior) AND ti(behav* AND health*)
S19	mjsub(health knowledge) AND ti(health* and knowled*)
S20	mjsub(health attitudes) AND ti(health* AND attitu*)
S21	mjsub(risk factors) AND ti(risk* AND factor*)
S26	mjsub(knowledge level) AND ti(knowled* AND level*)
S27	ti(colorectal* OR intestin* OR digesti*) AND (cancer* OR neoplas* OR carcino*)
S28	(S27 AND (S6 OR S7 OR S18 OR S19 OR S20 OR S21 OR S26))
S29	((S27 AND (S6 OR S7 OR S18 OR S19 OR S20 OR S21 OR S26))) and (pd(20000101-20170228))

* Duplicates are removed from the search, but included in the result count.

Duplicates are removed from the search and from the result count.

